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Article (Accepted Version)

D'Astous, Valerie, Manthorpe, Jill, Lowton, Karen and Glaser, Karen (2016) Retracing the historical social care context of autism: a narrative overview. *The British Journal of Social Work*, 46 (3). pp. 789-807. ISSN 0045-3102

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**Retracing the historical social care context of autism:  
A narrative overview**

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## Abstract

Autism is a lifelong neurodevelopmental disorder requiring various levels of social support across the lifecourse. Early cohorts of children first diagnosed as having autism are now middle aged or older. Needs for support and services, meaningful and accurate information and acceptance are substantial both among families supporting a person with autism and people with autism themselves. Social awareness and services for people with autism have changed over time; however, there is a paucity of reviews of the social context and services available since autism's 'discovery'. This narrative overview explores historically the social care services available to adults with autism and their families, in the context of changes in societal understanding and awareness of autism over time in England. Such an approach may contribute to understandings of older people with autism who have had a label of autism for many decades or who may have acquired this in later life. Retracing the historical social context and care services for autism contextualises the lifecourse experiences and interactions with social workers of today's adults with autism and their families. This review may assist social workers supporting adults with autism and their families to have a better understanding of service trajectories and why contact with professionals may be or has been varied and inconsistent. The key themes from this narrative review suggest the interconnections between scientific development, social awareness and service provision for individuals with autism and their families and changes in social care over time.

## Introduction

Autism is the name given to a lifelong, neurodevelopmental disorder that affects how an individual communicates with and relates to people and the environment (Rapin & Tuchman, 2008). It is a recently recognised disorder, identified in 1943 by American psychiatrist Leo Kanner. The first cohorts of children diagnosed with autism are now middle aged or older.

Adults with autism face challenges in activities of daily living, such as communication, socialization, learning, self-help, independent living and adaptation to change (Happé & Charlton, 2012).

Currently, no biological “test” exists for diagnosing autism (Baird, Cass, & Slonims, 2003). It is defined by a pattern of abnormal behavioural characteristics, ranging in severity from mild to severe (Centers for Disease Control and Prevention, 2012). Terminology for autism has evolved, with modifications of defining criteria (Ornitz & Ritvo, 1976; Rutter, 1968). Historically, autism has been named: childhood schizophrenia, infantile psychosis and infantile autism. Recently autism has been superseded in some debates by ‘autism spectrum condition’ (see Mills and Francis 2010) but this paper uses ‘autism’ to reflect current United Kingdom (UK) legislation. Although diagnostic modifications seek to define more specifically the parameters of autism, individuals diagnosed in the 1950s met very different diagnostic criteria than those diagnosed in the 1990s or later. Terminology and diagnostic criteria for autism have been analysed and reviewed in abundance (Charman & Baird, 2002; DeMyer, et al, 1981; Gillberg, 1990; Matson, et al, 2007; Ornitz & Ritvo, 1976; Rutter, 1968; Wing, 1993). However, there is no definitive treatment or medication that can ‘cure’ autism. Indeed, the concept of ‘curing’ autism is challenged by members of the autistic community (Kreck, 2013; Silverman, 2008) who describe their ‘disorder’ as a different way of seeing and experiencing the world.

Much debate exists over autism’s prevalence and whether it is increasing. Greater awareness, more inclusive diagnostic criteria, improved identification, recognition of permanency across the lifecourse, differing research methods and increases in service availability may account for increasing diagnoses of autism in children (Baird et al., 2006; Fombonne, 2003; Johnny L

Matson & Kozlowski, 2011). Thirty or forty years ago the diagnosis of autism was rare, with other mental illness diagnoses or the label ‘mentally retarded’ given. Children with severe autism were often institutionalised or kept at home. Today, the profile of childhood autism and its impact on families and services are better recognised. However, the autism rate has remained stable over decades in England with the prevalence of 1:100 adults being similar to that in children (Brugha et al., 2011). Others contend the prevalence rate has increased, citing unknown causes, including possible environmental factors (Matson and Kozlowski, 2011).

The interpretation of autism, since its clinical recognition and classification, accompanies progress in knowledge and therapeutic interventions. Numerous reviews have detailed scientific understanding (Bailey, Phillips, & Rutter, 1996; Newschaffer et al., 2007; Ratajczak, 2011) and clinical or therapeutic interventions (Gresham, Beebe-frankenberger, & MacMillan, 1999; Howlin, 1998; Howlin, Magiati, Charman, & MacLean, 2009; Matson, Benavidez, Stabinsky Compton, Paclawskyj, & Baglio, 1996; Prior, 1979; Seida et al., 2009; Silverman, 2008; Wenar & Rutterberg, 1969) highlighting changes over time. Social awareness and services have also changed over time, however there is a paucity of reviews of the social context and services for people with autism since its ‘discovery’ (Silverman, 2011) despite social care services being vital for many individuals with autism and their families (Department of Health (DH), 2010). In England the government has expressed policy commitment to improving social care and other services for this excluded group by issuing statutory guidance to local authorities and the NHS in its Autism Strategy (DH, 2010).

## Aims

The aim of this narrative overview is to explore historically the social care services available to adults with autism and their families, in the context of changes in understanding and

awareness of autism in England. Retracing the historical social context and services for autism through the published literature contextualises the lifecourse experiences and interactions with social workers of today's adults with autism and their families. This review may assist social workers to better understand service trajectories and why contact with professionals may seem varied and inconsistent. Furthermore, appreciation of the historical context may enhance funding of support for people with autism and their carers and further inform research or policy.

### Social care needs

Autism's effects for individuals and families may be profound; requiring support (from family members or others) to meet specific needs and achieve quality of life. The heterogeneity of impairments, strengths and comorbid conditions necessitates a wide range of support. While some individuals need little or intermittent support, others require substantial daily support. Similarly, carers may also have their own support needs.

While this review focuses on adults with autism and their family carers, many will have had formative experiences of contact with social work and other professionals in childhood or early parenting. The lifetime needs for support and services, meaningful and accurate information, and acceptance are often substantial among carers, as well as for people with autism themselves. Practitioners working with adults with autism and older carers may find this evidence helpful in understanding attitudes to help-seeking behaviour and (mis)trust of professionals.

Adequate and effective social support reduces stress and improves wellbeing for parents of children with autism (Nealy, O'Hare, Powers, & Swick, 2012; Siklos & Kerns, 2006). Over the

longer term it may help minimise the general level of disability associated with autism. For over a decade policy has emphasised the need to support such parents (DH, 2004).

In this paper the social context includes the social care and support that could be potentially provided, received or needed by individuals with autism or their carers. Social care covers a broad range of interventions in the UK and typically is distinguished from healthcare. Generally, social care is defined as the provision of personal care, protection or social support services to adults in need or at risk (see The Care Act 2014). Social care services may include home or residential care, employment support, and community support to meet individuals' desired outcomes and support their wellbeing. This encompasses practical and emotional support for people with disabilities, elements of information and advisory services, advocacy, and support for carers. The social care services considered here include practical, informational and emotional support provided by social workers and other social care practitioners. Such services, in cash or in kind, are publicly funded in England subject to need and financial grounds. For adults, most publicly funded social care in England is provided by the private sector although increasing numbers of people make arrangements themselves (through direct payments, personal budgets or self-directed support) (Health and Social Care Information Centre, 2013).

Models of disability detail the profile and understanding of disability and outline the social, political, cultural and economic environment in accordance with different perspectives (Shakespeare, 2006). Several disability models have been suggested and two are prominent in social work as polar opposites, the 'medical' and 'social' models. However, models' development and popularity reflect changing social attitudes to disability. The prevailing model

of disability provides insight into the attitudes, conceptions and prejudices of the time and the contexts in which social workers practice.

## Methods

A broad perspective of the historical context of autism was achieved through a systematic search and narrative review of research reports, grey literature, and English government policy and legislation. Additionally, a hand search of the literature supplemented database findings. Parental and individual accounts are included to offer user and carer perspectives. In 2013 members of the Social Work History Network were asked by email request “to share their memories and experiences of social service availability for children with autism and their families in the 1950s, 60s and 70s”. Eight replies were received. Illustrative quotations from these UK social workers are used anonymously with their permission.

Five databases (Medline, PsychInfo, Embase, CINAHL, and Proquest) were consulted, with the subject heading and key words of “autism”, “infantile psychosis” and “social care services” searched (See Box 1). An English language restriction and year restrictions of 1943-2013 were applied, generating 160 items. In addition, hand searches of the references of retrieved literature and personal and university libraries located 59 further texts. Titles and abstracts of the identified studies were screened for relevance using a broad inclusive criterion. Finally, a more rigorous screening was achieved, searching each item for aspects of social care services, availability and/or use, autism and family support, and social policy on autism. After screening and removal of duplicates, 64 relevant articles and eight grey literature texts were read in their entirety. Additionally, 11 UK government policy documents were reviewed (See Table 1).



## Box 1

### Sources accessed

Key words: “autism”, “infantile psychosis” and “social care services”		
English language		
Source	Search period	Number of texts
Medline	1946-3 <sup>rd</sup> week November 2013	18
PsychInfo	1943-2 <sup>nd</sup> week December 2013	48
Embase	1947-2 <sup>nd</sup> week December 2013	23
CINAHL	1997-2013	49
Proquest: Applied Social Sciences Index and Abstracts (ASSIA)	1989-2013	22
Hand searches - personal and university libraries		59
Expert opinion included: texts by parents and individuals with autism and discussions with social workers of practice experiences		

### Findings

The review findings are presented in three timeframes to draw attention to the changes over time and the bi-directional interrelationships between scientific knowledge, social awareness, social care and public policies.

#### The early years – 1943-1970

##### Scientific development

In this period the medical profession considered autism to be a rare psychiatric condition with poor outcomes, and the public considering it a social embarrassment (Lotter, 1966). To early clinicians and researchers, autism was linked to schizophrenia (Silverman 2011) and, until the mid-1960s, undifferentiated from mental retardation and/or mental illness. Institutionalisation was often recommended as the best ‘solution’ for the family (Bettelheim, 1967b; Rutter, 1974).

Working within the prevailing Freudian ego psychology paradigm of the time, the infant's psychic development was thought to depend on the mother's degree of empathy and attunement to her infant (Astis, 1997). Thus, clinicians held that, as a result of poor mother-child relationships, children's ego development was inhibited, with childhood psychosis ensuing. Bettelheim (1967), an American child psychologist, extended this belief with his theory that children develop autism as a result of cold, uncaring mothers. He argued that traumatized, unloved children of 'refrigerator mothers' were more likely to become autistic than others (Bettelheim, 1967b), and prescribed removing the child from the parents with an indefinite term of therapeutic institutionalisation (Bettelheim, 1967a; Schopler & Reichler, 1971). The stigmatising mark of a 'refrigerator mother' and parental blame pervaded professional training: *"We were taught this as gospel"*, recounted one member of the Social Work History Network. Autism was considered a child's defensive reaction to a parent's (usually the mother's) 'psychotoxic' relationship (Fraknoi & Rutter, 1971). Parental feelings of guilt and failure were reinforced by the causal understanding and blame attributed by professionals and the lack of knowledge about autism generally. Another social worker's recollection expressed this well, *"I know someone who worked in a residential home for children at the period who said that idea [of blame] was so widespread that parents were rarely offered help because they were seen as the cause"*.

#### Social awareness and service provision

In her book *Involuntary Strangers, Autism, The problems faced by parents*, Everard (1980) recounted her experiences of raising her son with autism, born in 1952. She recounted feeling very alone, receiving no help or encouragement when he was a child. Parents then had very little means of receiving support and/or learning from other parents. Overall, many children with learning difficulties did not have a right to an education at this time. Everard explained,

*“At five, the age that children must enter school, the local authority acknowledged his existence by asking me to take him for an IQ test at the clinic. In 1957 mentally handicapped children were sorted into those who were considered ‘educable’ that is, those with an IQ of 50 or above and ‘ineducable’ those who had an IQ below 50”* (p43). Thus contemporary scientific thinking and social policy influenced the context of limited care or support available to children with autism and their families. Those accommodated in long-stay hospitals were expected to remain for life. Moreover, the medical model of disability conceptualised the disability of autism as an individual ‘problem’ (Shakespeare, 2006). Under the medical model, impairments or differences were to be fixed or treated by medical interventions (Crow, 1996).

In this era only a minority of children received a specific autism diagnosis. Undefined diagnostic criteria compounded its precarious acceptance within the medical and scientific community and limited its understanding and awareness. *“Because so few people were given a diagnosis then, most people with autism in that period would be ‘hidden’ in data records of the period”*, stated a third Social Work History Network member. Furthermore, many children were classed as *“hopeless”* with custodial care in a mental handicap hospital or hospital for the subnormal authorised. Wider social awareness of autism was negligible. It appears that parents during this era were isolated, with few resources or information to help them. When parents were believed to have caused their child’s autism they were scrutinised, treated, researched and stigmatised by both professionals and the public (Fraknoi & Rutter, 1971; Gray, 1993).

The negative views of mothers of autistic children gradually attracted criticism. A seminal study by Creak and Ini (1963) found no evidence of a parental personality stereotype as psychologically damaging and causal of autistic children. Further studies supported their work,

finding no such personality type among mothers (Kolvin, Garside, & Kidd, 1971; Pitfield & Oppenheim, 1964; Rutter & Bartak, 1971). Rimland (1964), an American psychologist and a parent of a son with autism, refuted that he or his wife were ‘refrigerator parents’ and was one of the first to propose a biological basis for the disorder. He argued that autism was a biological disorder, not an emotional illness.

Yet still, parental psychogenic blame was redefined by some behaviourist psychologists as parental behavioural blame, such that poor parenting skills reinforced the disruptive behaviour of autistic children (Ferster, 1961; Rutter, 1968). This parental blame acted as a double-edged sword; on the one hand a parent was still culpable for their child’s disorder and on the other, if a parent was the cause, there was the possibility of a therapeutic cure. Thus, over time the clinical focus shifted from a psychogenic, unfixable paradigm to a behavioural, fixable model. Along with reports of effective training and teaching methods for teachers and nurses, parents were beginning to be considered as partners and were taught to assume a role of co-therapists in their children’s learning and behaviour modification programmes (Koegel, Glahn, & Nieminen, 1978; Schopler & Reichler, 1971).

Following an interview on BBC radio’s Woman’s Hour in 1961, a group of parents of children with autism, seeking support and information, formed a self-help group, which became the National Autistic Society (NAS) (NAS, 2013). Their mission was to raise public awareness of autism and to provide information and advice for parents. They successfully lobbied government to include autism as a developmental disability, as added into the Education (Handicapped Children) Act (1970), which enabled children with autism amongst others to access more appropriate education.

## Social care

Professional social support emerged in 1967 when a Child Guidance Special Interest Group (CGSIG) was established by Psychiatric Social Workers to meet the needs of ‘disturbed’ children (Younghusband, 1978). Its members included social workers, working with families of these ‘disturbed’ children, who offered advice and information about community resources and supportive parent organisations (Younghusband, 1978)). The Local Authority Social Services Act (1970) established a single social services department in each local authority, emphasising the need for a co-ordinated and comprehensive approach to supporting families, detecting need, and encouraging help-seeking (National Archives, 1970).

Over this time alterations in the scientific understanding of autism, parent advocacy and social changes combined to create a more responsive environment for children with autism. However there is little evidence from this period about the social care of adults with autism save that they were likely included among ‘mental handicapped’ long-stay hospital patients or visited in family settings by mental welfare officers.

## 1970s-1990s

### Scientific development

This period witnessed expanded scientific and medical understanding of autism, increased public awareness and new directives in social care services. Autism began to be understood as a neurodevelopment disability (Folstein & Rutter, 1977; Rutter, 1974); an impairment in the growth of the brain and nervous system. Wing (1993) introduced the concept of autism as a spectrum producing a wide range of cognitive and neurologic impairments, expanding the recognition and inclusion criteria for diagnosis.

## Social awareness and service provision

Community care policies, notably the deinstitutionalisation or long-stay hospital closure programmes of the mid-1970s, prompted radical transformations in societal views of developmental disorders (Eyal, 2013), moving care and support decisions away from healthcare professionals to local authorities. Acknowledgement of the extraordinary stress experienced by many families caring for an autistic child or adult was supported by growing evidence about the general stresses of caring. Social support was shown to lower stress levels in parents of children with autism (Bristol and Schopler, 1984), but was in short supply. Lack of information and support was demonstrated to contribute to parents' burdens (Heller & Factor, 1993). Diagnosis and intensive therapeutic interventions seeking to diminish 'non-normative' behaviours and to promote approximate 'normal' behaviours underscored the medical model of disability.

Awareness of autism heightened during this period and autism research increased dramatically. The popular film 'Rain Man' (1988), about an autistic savant man, helped propel autism into the public's purview. It is in this timeframe that the first books written by authors with autism began to appear (Grandin, 1995; Williams, 1992). The NAS continued to increase awareness, encourage research, and press for government initiatives, such as services for people with autism and their families. It opened schools and residential communities and set up a national telephone helpline. The NHS and Community Care Act (1990) empowered local authorities to assess adults' need of care services, including individuals with autism. Those eligible might be supported by a care manager or social worker in a specialist team (some including healthcare professionals). Furthermore, the Carers (Recognition and Services) Act (1995) offered people providing substantial care on a regular basis the right to assessment of their own needs. Advocacy and legislation promoting awareness, social rights and inclusion of people with

autism are aligned with the social model of disability and illustrate its emerging influence. The social model proposes that society creates disabling barriers for people with differences or limitations (Watson, 2007). These barriers may encompass physical limitations in the built environment, inflexible policies, practices or procedures, and social attitudes, including prejudice, stereotype and stigma (Office for Disability Issues, 2010).

#### Social care

Development of community care and long-stay hospital closures, combined with the shift to commercial social care services, placed social workers in new roles as gatekeepers of local authority funding and as care managers with responsibilities for assessment, care planning and review (Burnham, 2012). A Joint Circular (Department of Education and Science (DES)/ Department of Health and Social Security (DHSS), 1974) on the role of social workers acknowledged “*They have contributed to the development of services for children and their families...*” (p.4). However, it observed that, “*there was a serious shortage of [these professionals]*” and declared a need to “*extend help to more children with behaviour, emotional or learning difficulties and their families*” (p.5), which was noted as important for the profession (Black & Harris, 1978; Younghusband, 1978).

#### The year 2000 to date (2014)

##### Scientific development

Understanding the aetiology of autism is critical for developing effective interventions, yet despite extensive research, specific cause and risk factors of autism remain elusive. Autism is now defined as a complex neurodevelopmental disorder with genetic and environmental causal factors (Currenti, 2010). It is no longer considered a rare condition with diagnostic prevalence rates having increased dramatically (Fombonne, 2003; King & Bearman, 2009). Greater

medical awareness, changes in diagnostic criteria, and more sensitive screening may have contributed to this increase.

#### Social awareness and service provision

The growing separation of children's and adults' social services appears to have challenged continuity of social work services (Allard, 2009). The White Paper *Valuing People* (DH, 2004) declared that everyone with learning disability should have access to community-based multi-disciplinary care; significantly autism was included but was quickly to assume a policy focus of its own.

NAS efforts promoted the Autism Act (2009), which outlines government responsibilities for support for people with autism and their families. This was followed by the first Autism Strategy, *Fulfilling and rewarding lives: the strategy for adults with autism in England* (DH, 2010) a landmark document in its creation of a separate policy framework and long-term ambitions, overseen by an Adult Autism Programme Board (DH, 2011) which includes self-advocates and carers as well as a Ministerial chair. Currently social work practice with people with autism, as with other disabled adults, is focussed on personalisation – although the scandal of Winterbourne View private hospital has necessitated greater involvement in more focussed care planning for people with complex or severe disabilities including autism (DH, 2012).

While early advocates for people with autism were parents, practitioners and researchers, during this period organisations such as Autism Network International, the Autistic Self-Advocacy Network and the Global and Regional Asperger Syndrome Partnership have been established by and for people with autism. Increasingly people with autism have begun to



express and share their perspectives and concerns (see James, 2009). Some take an active role in relevant public policy, research, service delivery and media discussions.

From the perspective of the social model of disability autism may be considered a different way of interacting and relating to the world, one that should be accepted and accommodated by society (Krcek, 2013, Silverman, 2008). Thus, it is not autism that limits an individual's societal engagement but rather society's exclusionary structures and attitudes. Removing barriers through supportive services and adjusting environmental spaces to accommodate sensitivities of people with autism illustrate structural changes in accordance with the social model of disability and are inherent in the Autism Strategy (DH, 2010) which should underpin practice.

#### Social care

As with other parts of social work, assessment remains a key role (Saeki and Powell, 2008) and continues with the transformation of care management processes to personalisation, notably the encouragement of individually-constructed goals, tailored support plans to meet outcomes, facilitated by personal budgets paid to eligible people or their proxies (DH, 2010; Mills and Francis, 2010). Social care practice also changed with the introduction of the Mental Capacity Act (2005) in England and Wales and its amendments, giving rise to roles such as Best Interests Assessors and statutory advocacy for the minority of adults with autism lacking specific decision-making capacity. The rise in adult safeguarding as central to the social work role has also potentially impacted people with autism although safeguarding data by this classification are not specifically reported for this group.

The covert filming exposing the abuse of people with severe learning disabilities at Winterbourne View private hospital (Dale & Ryan, 2011; Flynn, 2012; Hughes, 2012) and the preventable death of Connor Sparrowhawk in 2013 (Hughes, 2014), a young man with autism, at Slade House, an NHS assessment and treatment unit, highlight failures in planning, monitoring, safeguarding and commissioning processes of health and care services and present valid concerns for ageing parents of adults with autism in need of support. Respecting human rights within a framework of collective responsibility may help maximise social inclusion, autonomy and wellbeing. Social workers and other professionals need to incorporate a person-centred approach in practice, with the adult with autism as the focus of the support plan, family involvement as experts, and advocates and community connectedness to achieve optimal emotional, physical and social support and wellbeing. However the lack of resources available to people with autism and their carers is brought into sharp relief. As Fernandez et al (2013) have shown, in England there is diminishing support for older people from local government services. This may affect social workers' and other professionals' abilities to provide access to social care support for older carers and people with autism themselves.

Table 1: Key policies and legislations (England) relevant to autism

Policy/ Legislation	Date	Service Provision
Health & Social Care Act	1948	Inception of National Health Service
Education (Handicapped Children) Act	1970	Discontinued classification of handicapped children as 'unsuitable' for school education
Children Act	1989	Promotion and safeguarding of children in need
NHS & Community Care Act	1990	Community care assessment, care management and review introduced
Carers (Recognition and Services) Act	1995	Carer's assessment to be offered with practice guidance restrictions (i.e. person caring for must be receiving assessment, providing substantial care, contracted to provide care, must request carer assessment)

Carers and Disabled Children's Act	2000	'Free-standing' assessment and services to meet needs of carers and disabled children (removed previous Act restrictions, carer now entitled to community care assessment in their own right)
White Paper: Valuing People	2001	Access to community-based multidisciplinary care for all people with learning disability
Mental Capacity Act	2005	Framework for adults lacking decision-making capacity
Autism Act	2009	Provisions to meet needs of adults with autism
Autism Strategy	2010	Outlines planning and implementation goals of services for adults with autism
Care Act	2014	To promote well-being, develop responsibilities for safeguarding, care and support for adults and carer; legislation consolidated, emphasis on personal budgets and integration

## Discussion

The key findings from this narrative review highlight: the interconnections between scientific development, social awareness and services for individuals with autism and carers; and changes in social care as the context for social work practice. When autism was considered psychogenic in origin, stemming from poor mother-child relationships, there was little social understanding and limited social care for individuals and carers. Possibly linked to scientific advances in the 1960s and 1970s, parental blame and stigma diminished, parents of children with autism sought support, exchanged information, and increased awareness of autism. In this timeframe social workers' contributions to service development for children and their families was further expanded as deinstitutionalisation and community care policies progressed. As autism began to be understood as a neurodevelopmental disorder, parental stress associated with raising a child with autism was acknowledged, with social services assessment and entitlements enacted under the NHS and Community Care Act (1990), the Carers (Recognition and Services) Act (1995) and, more recently, the Care Act 2014.

A historical perspective on the social context of autism based on academic and grey literature needs to encompass personal narratives from parents and professionals. Parents who were once considered the cause of their children's autism (and thus often distanced from them), are now theoretically included as partners in their children's lifetime care. Children with autism, once excluded from society, then consigned to special education with intellectually and physically disabled (using contemporary terminology) children, are now often integrated in mainstream general education, training and community activities. However, for older people with autism, and older parents of an adult with autism today, experiences or absences of social care and support may have lasting implications on their engagement with current and future social workers.

Inadequate social supports for parents, poor societal awareness and limited understanding of autism are considered among the most stressful aspects of parenting a child with autism (Gray, 1993; Sharpley, Bitsika, & Efremidis, 1997). Through practical, informational and emotional support and effective social care and social work support these stresses may abate; this is a dominant motif of current policy for carers of individuals with autism. Stress reduction and improving outcomes overall are typified as the goals of practical and emotional support, education, information and respite (short-breaks). More recently, personal budgets may contribute to highly person-centred support for people with autism and their carers (SCIE, 2010). It remains to be seen whether policy commitment to widen the availability of personal health budgets will give individuals with autism and their carers greater scope for choice and control (Health Foundation, undated).

The impetus for change in awareness and articulation of rights to social care for people with autism continues to be the advocacy of parents (Silverman, 2011), many of whom have resisted

biomedical definitions, remedies and clinical perspectives. Through advocacy, parent associations provided the momentum for policy change, encouraged and funded scientific research, raised public awareness, and provided information and support for people with autism and their carers. For older people with autism, as with other older people with disabilities, the commitment of their parents to advocacy and care may be hard to replace, as they themselves realise (Dillenburg & McKerr, 2011). As Silverman (2011) observed, parents are the main sources of expertise about their children. If they die or lose this memory then this expertise, commitment and love potentially disappear.

There are several limitations to this review that may have influenced our conclusions. Although a systematic search was conducted using various search terms, some relevant studies may have been missed that could modify these conclusions. The subjective nature of a narrative review methodology is limiting; the determination of which studies to include, how they are analysed and the conclusions drawn may reflect research and selection bias. However, personal experience and practice knowledge from social work professionals, together with parents and people with autism as users of social work services, were used to enrich the review's findings. However, missing from this paper and indispensable for a comprehensive history are the viewpoints of people with autism.

## Conclusion

This review builds upon the knowledge base and the historical context of autism in England through the compilation of narrative accounts and literature of scientific and societal understanding of autism and social care provision over time. Through the actions and voices of individuals and groups advocating for change, coupled with knowledge advancement, the social environment of autism today is very different from that of 70 years ago. Likewise, social

work practice has also evolved. However, despite improvements in services, recognition and inclusion for children with autism, social care services and support for adults with autism remain inadequate (Cadman et al., 2012). Recent policy commitments expressed in the Autism Strategy (DH, 2010) and the Adults with Autism guidelines (Wilson et al., 2013) offer opportunities to improve outcomes and to develop professionally useful quality indicators. As in many other practice arenas, policy aspirations and mandates seem difficult to translate to service or professional resources.

The experiences of older people with autism and of older parents in providing continuity of care for their adult children cannot be entirely generalized to younger people with autism and current cohorts of parents of an adult with autism. Older parents' attitudes to social workers may be affected by difficulties that carers, especially parents, have encountered historically, leading them to believe that social workers lack understanding of autism and its symptoms. As Taylor and Marrable (2011, p44) observed, '*carers can be under the impression that social care services are seeking to marginalise them or add to their burdens*'. Social workers may need to counter such fears through the development or sustainment of trusting, person-centred relationships and good practice, and to openly address the problems exposed in media scandals without giving false assurances. This narrative overview may enable a more holistic understanding of this client group. Acknowledging the past can help with an appreciation of the present and illuminate the way forward. Taking a lifecourse perspective, and developing knowledge and understanding of the shadows of parent blame and challenging the sustained social exclusion of people with autism may be helpful to practitioners new to this area of practice.

**Acknowledgements and disclaimer to be inserted**

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